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LETTER TO THE EDITOR

SUDEP in the Netherlands

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Risk factors

We would like to respond to the letter sent by Dr. Bell and Dr. Sander on 6th March.

Firstly, the establishment of survivor status for all attendees of the tertiary referral centre for epilepsy is questioned. Through the electronical patient record system, which is continually updated, we obtained an exact number of deaths in our patient population. Consequently, there is no reason to believe an underestimation of death rates has occurred. The number of patient years was derived from the number of patients attending the epilepsy centre during the period under study. Again, the electronical patient record system provided reliable numbers of attending patients. A mean number of 4400 people with epilepsy were treated per year. The majority of this population is receiving chronic treatment for their epilepsies. Another part of the population stays under the attention of the epilepsy centre for a shorter period, but there is a steady turnover of these patients which is illustrated in the mean number of attending patients.

The study period comprised 5.3 years resulting in 23,230 patient years. With 29 definite and probable SUDEP cases, the SUDEP rate of 1.24 per 1000 patient years was calculated. If we would have included only definite SUDEP cases, the SUDEP rate would have been even lower, that is 0.21 per 1000 patient years, but we believe this would be an actual underestimation of SUDEP. If we would have obtained exact patient years of follow up, perhaps we would have obtained a slightly lower number of patient years resulting in a somewhat higher SUDEP rate, but almost certainly not in excess of 1.5 per 1000 patient years.

The choice for the non-SUDEP deaths as controls can be justified in different ways. The aim of the study was to identify risk factors for SUDEP in an already high-risk population. Hence, patients attending a tertiary referral centre frequently suffer from refractory epilepsy and, consequently, are on AED polytherapy. With this study, we hoped to identify the factors that possibly predict a patient with epilepsy to be prone of SUDEP. Using the non-SUDEP deaths as controls, a group of patients with epilepsy is explored that is comparable to the SUDEP group, with the difference that they died due to other causes and not SUDEP. Differences in individual or epilepsy characteristics between those two groups, would show the risk factors for SUDEP. Eventually, we were not able to identify such risk factors.

We understand the obtained SUDEP rate is unexpectedly low and not comparable to the rates achieved in countries such as the United Kingdom. Possibly differences in the health system are one of the factors contributing to this considerable difference in SUDEP rate.

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